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ABSTRACT

Excerpts are given of presentations and discussion from the 1979 Puerto Rico conference on international developments in mental retardation. R. Dybwad ("The Child with Retardation Today--The Adult of Tomorrow") briefly reviews international issues, including self advocacy and problems of world poverty and malnutrition. M. de Trias lists ideal elements in intervention for families ("The Family--Growing Together"). In "Education for Living," L. Brown describes key elements in education for the handicapped, including zero rejection, a normal ratio between those with handicaps and those without, and natural environments. W. Eigner predicts the development of programs--especially industrial ones--for adult handicapped persons. B. Speake examines the work environment of the adult with retardation. A final paper, by J. Dickey, et al., presents quotes and thoughts from 30 persons with mental retardation on such topics as segregation, powerlessness, and self advocacy. (CL)

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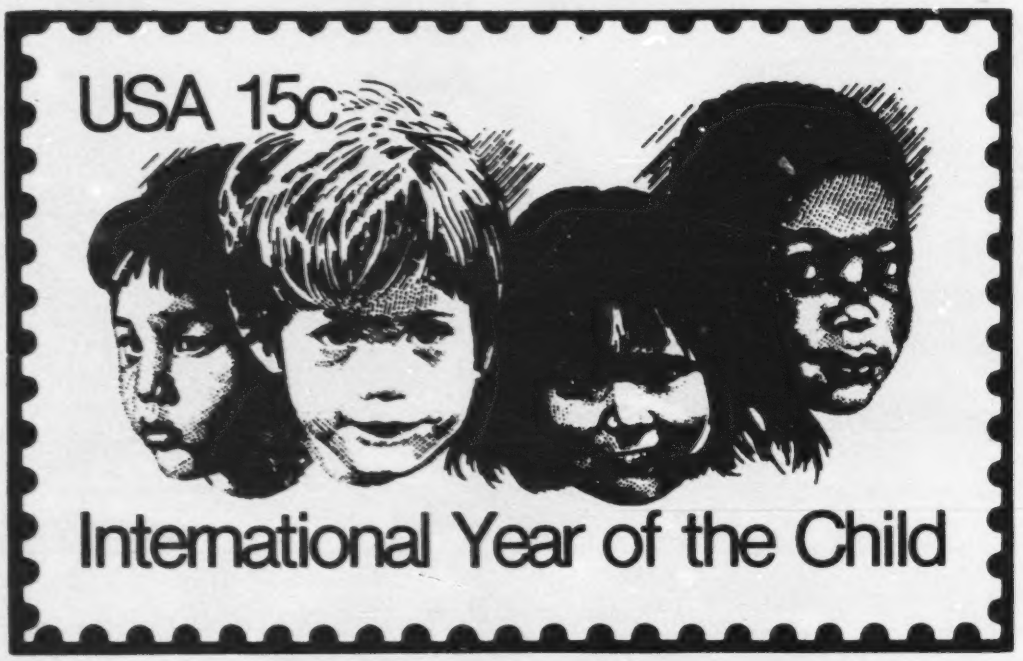

THE ADULT OF TOMORROW

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International Year of the Child 1979

Ano Internacional
da Criança 1979

Año Internacional
del Niño 1979

Anno Internazionale
del Fanciullo 1979

A SYMPOSIUM COMMEMORATING THE INTERNATIONAL YEAR OF THE CHILD — 1979

San Juan, Puerto Rico
November 12-16, 1979

Hosted by the ARC National Research and
Demonstration Institute
on behalf of
The International League of Societies for the
Mentally Handicapped

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Eleanor Elkin, Symposium Chairperson
Liz Pippin, Project Coordinator
Robert Perske, Symposium Editor

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PREFACE

"Will the speaker please slow down? The interpreters cannot keep up." This request was heard many times during the symposium. People traveled to San Juan from many different parts of the world to share information on what was happening to persons with mental retardation in their part of the globe . . . . And they had much to tell . . . . And the time was short. It was a simple case of enthusiastic sharing, and since time was precious, nobody wanted to waste it.

The differences between the participants were vivid:

They spoke languages ranging from the well-known English, French, Spanish and German to the Papiamento language of the Netherlands Antilles.

Some came from nations which existed for centuries — like Austria, Spain and the United Kingdom — while others, like Kenya, are breathing the breath of new life.

Some lived in countries where governments spend millions on services for persons with handicaps while others came from settings where only meager amounts are spent for such efforts.

Some lived on large continents like Canada and the United States, while others were at home on such islands as Martinique and Puerto Rico.

But in spite of these differences, they possessed one thing in common: a fierce determination about raising the quality of living for persons with mental retardation throughout the world.

In the first session, the point was made that some persons have been so stigmatized as retarded during childhood that all chances of their achieving full status as adults are snuffed out. The participants threaded this haunting point into every session like a composer develops a single melody which reoccurs throughout an opera.

Each session was conducted according to the following plan:

- The working papers[1] came to the participants weeks in advance, giving them the opportunity to read them prior to the symposium.
- Consequently, presenters took only ten minutes at the beginning of a session to summarize or add information.
- One discussion leader and two recorders were appointed for each session from among the participants.
- During the evening hours, the discussion leader, recorders and presenter met and drafted a report of the session discussion.
- Then each report came before the larger assembly for final discussion and modification.

This symposium was richly influenced by the new directions emerging at the Seventh World Congress of the International League of Societies for the Mentally Handicapped, October 1978, at Vienna, Austria.[2] Also, when one reads this report and compares it with the reports of previous symposia — like the one held at Airlie, Virginia, USA[3] — one can see how insights gained at San Juan were gleaned from seeds sown in many previous meetings of the ILSMH. Now, it can be expected that this symposium will influence others that will follow.

[1] A limited number of single copies of the working papers can be obtained by writing the Association for Retarded Citizens National Headquarters, P. O. Box 6109, Arlington, Texas 76011, USA.

[2] The Proceedings of the Seventh World Congress can be purchased from Lebenshilfe fur Behinderte, Ebendorferstr. 10, A-1010, Vienna, Austria. Price: 230 Austrian Shillings (about $18.00 U.S., including postage).

[3] Improving the Quality of Life: A Symposium on Normalization and Integration can be purchased from the Association for Retarded Citizens National Headquarters, P.O. Box 6109, Arlington, Texas 76011, USA. Price: $1.25 U.S.

The International Year of the Child marked the 20th anniversary of the United Nation's ratification of the Declaration of the Rights of the Child. This motivated some representatives to consciously compare today's attitudes toward persons having retardation with those of 20 years ago.

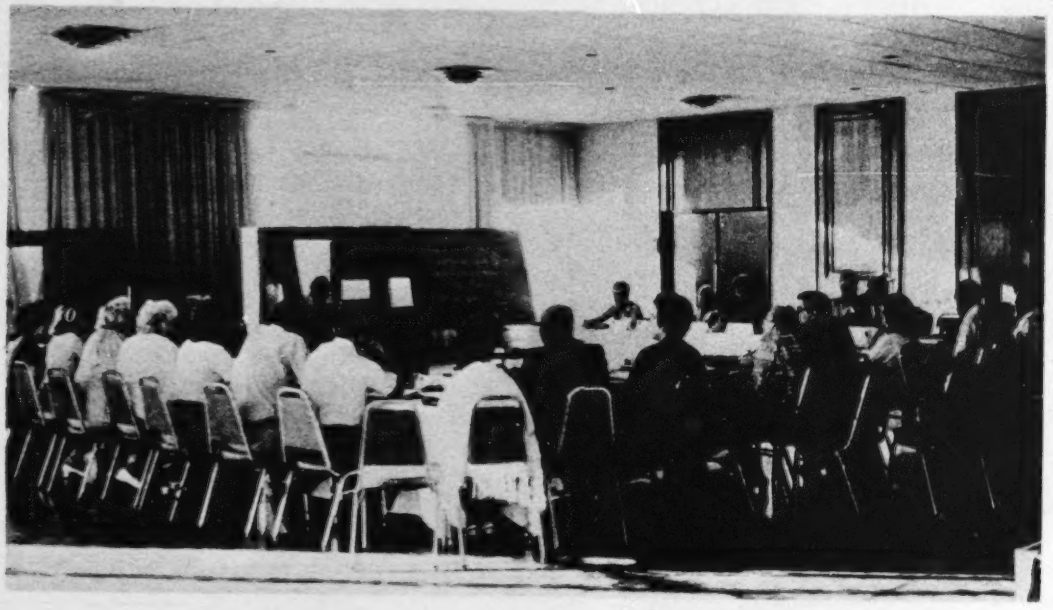
During the days at San Juan, a thought initiated in an earlier session often reoccurred, receiving further elaboration in a later one. Such step-by-step building of concepts caused overlaps. However, to take all concepts and organize them into discreet categories would hinder the reader's profiting from the valuable thinking process which went on throughout the week.

This report uses a special formula for the **dignified** addressing of persons with handicaps. The description and rationale of this formula can be found in the report on the first session (see topic, **People first**).

When the symposium ended and I packed my recording equipment, I felt respect for these committed people. Most were strangers to one another a few days earlier. Nevertheless they seized issues and worked on them together as if they had known each other for years. When it came to mental retardation, they spoke the same language.

Journalists often type citizens of various countries as being members of the first world . . . the second world . . . the third world and so forth — as if our common **terra firma** consists of a series of separate units. Their listening, empathizing, reinforcing and sharing proved to me that they are, indeed, members of the same world.

Robert Perske
Symposium Editor



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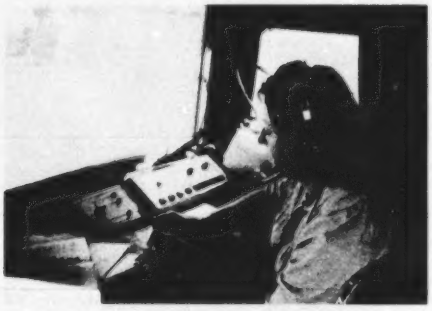

THE CHILD WITH RETARDATION TODAY — THE ADULT OF TOMORROW[1]

There is a difficult valley every child must cross before becoming an adult. Even the strong have problems traversing it. And for those with mental retardation, it often becomes a trap. Using the word pictures of journalist/advocate Ann Shearer, the presenter focused the attention of everyone on this critical situation:

"Mentally retarded persons are all too often caught in a half-world between childhood and adulthood, fitting into neither, frozen into a continuous state of becoming prepared to enter adult life, yet not enabled to reach it."

The representatives agreed this was the central issue to be faced. It caused basic questions to emerge. "How can we best prepare children with retardation to face this half-world? How can we help them to get through it and to emerge as full-fledged adults when they do?" Such questions remained uppermost in the minds of the presenter and the participants as they shared as many issues, ideas and successes as they could. In doing so, a larger picture was created, surrounding this single critical situation.

* * * * *

They are not eternal children. Not so very long ago, people saw persons with retardation as children who never grew. Now that view is changing. Many participants described how their own countries had just outdistanced the era when people with retardation were seen as eternal children. This realization made discussions about a full and healthy childhood more intense. After all, childhood is s formative period . . . and the time of childhood should never be wasted.

Organizations modify titles. Many voluntary associations throughout the world are dropping the words **child** and **children** from their organization's name or — like Sweden — they are expanding the title to include **adolescents** and **adults**. All representatives welcomed such changes.

World poverty and malnutrition: haunting problems. The presenter described a tragic dilemma that is happening in the world today. First, she shared passages of a letter from a colleague traveling in India:

"As you know quite well, the poverty is so severe in India that it is difficult knowing where to start. All efforts being done to help the poor are just scratching the surface of the known need . . . . When basic needs of food, shelter and clothing are not being provided for so many millions, it would be difficult to spend limited resources on training handicapped persons. In India, they must spend their time on issues relating to life before they can address the issue of the quality of life."

Then she provided another perspective:

"I am not surprised about his reaction because it is shared by many of our colleagues . . . . In the first place, while it is true that in India people are starving . . . there are also cities like Bombay, Bangalore and Delhi where large numbers of people live in comfort, have university education and if they have a handicapped child with blindness or mental retardation, like similarly situated parents elsewhere in the world, they want their child to have health and educational services. Indeed there are more than one hundred specialized programs for retarded children and adults in India. How can all this be reconciled?"

The representatives agreed that every nation must work to decrease the pangs and frustrations of hungry stomachs and shivering bodies everywhere. And yet, while struggling with the larger situation, they chose to emphasize two specific principles:

- **All mothers and infants have crucial needs.** There is a need for adequate maternal nourishment, prenatal services, proper assistance at the time of birth, sufficient infant nourishment as well as adequate support and training services for both the mother and the infant. Every

[1] *Based on a working paper by Dr. Rosemary F. Dybwad (United States).*

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mother and child on the face of this earth — no matter what their social status — have a crucial need for such help if the children will truly be prepared to live full, healthy lives as adults — and to even reach adulthood.

- **Scarce resources shall be shared by all, handicapped and non-handicapped.** In planning for the future, integrated rather than segregated experiences will bring the greatest human benefits to our children, whether handicapped or non-handicapped.

Developing countries have much to give to the world. The old we-have-something-to-give-to-them-but-they-have-nothing-to-give-in-return attitude of industrialized nations is diminishing.

Even countries almost overwhelmed by poverty felt they had something to tell the world about valuing persons with handicaps, developing techniques for community-based services, inspiring fresh volunteer efforts, and creating indigenous solutions. It can be expected that more and more participants from emerging countries will be present at ILSMH symposia and the interactions between them and those from industrialized nations will possess a candid, two-way flavor.

Breakthroughs benefiting adults emerge everywhere. More attention is being placed on the situations of adults than ever before. Consequently, numerous new concepts and schemes are being developed:

- In South Wales, a "Pathway Scheme" uses a regular employee to guide a new employee with a handicap into making a success of his job. For three months, the regular laborer serves as a part-time "foster worker" who befriends, counsels and advocates for the new employee. He clarifies and helps solve every issue that arises from fellow workers, management or the new employee himself. The foster worker is paid a small sum for his efforts.
- Tunisia, according to one report, has no sheltered workshops at all. Persons with handicaps undergo training and integration in regular work settings.
- A high point at the International Labor Organization's Regional Seminar in Jamaica came when participants were challenged to give up stereotyped thinking suggesting that the best comprehensive programs end with sheltered workshops. Approximately 24 non-sheltered work opportunities were mentioned at the ILO meeting. This moved the participants at San Juan to call for an exhaustive list of such non-sheltered jobs that are being performed throughout the world.
- Agricultural work is making a remarkable come-back. Many experts heretofore shunned such vocations because of earlier bad experiences when large institutions owned farms, and the residents were forced to function as unpaid laborers. Now, however, new, dignified and skillful agricultural training centers — like Lufton Manor in Southwest England — are being developed in several parts of the world.

These vocational training opportunities, and more like them, are ushering in a new day for adults with handicapping conditions.

Regular educators rise to the cause. Twenty-five years ago, Professor Jack Tizard of New Zealand and England predicted the next major step in the education of children with handicaps would come from regular educators. Today, it is happening. For example, in Italian school systems, children with handicaps are not only being integrated in regular schools — they are being placed in regular classes. Integration takes place even for those with severe handicaps. This program of merging carries some interesting components:

- Regular schools are developing their own public attitude change programs which benefit persons with handicaps.
- Regular teachers are **volunteering** to take a child with a handicap — mild or severe — into their regular classes.
- Teachers who volunteer receive fewer pupils in their class (average reduction from 24 to 20 pupils) and they receive a part-time support teacher (average: one-fourth time).
- Support teams of professionals involve themselves with classes containing students with handicaps as well.

The report on the Italian educational breakthrough was prepared by Dr. Yvonne Posternak[2] under the auspices of the Organization for Economic Cooperation and Development.

[2] **Posternak, Yvonne. The Integration of Handicapped Children and Adolescents in Italy.** *Centre for Educational Research and Innovation, OECD, Chateau de la Muette, 2 rue Andre Pascal, Paris XVI, France.*

Professor Tizard involved himself in this project until his untimely death in August 1979. It must have pleased his pioneering spirit to see such integrations taking place.

People first. The summarizing report called for addressing people with handicaps according to a special formula: "It is best to emphasize **person, people** or **citizen** and, if necessary, **with retardation** (or whatever handicap) afterward. Talking about a **person with retardation** is much more dignified than saying **the retarded** or **the retarded person.**"

Representatives described how the way people are addressed can determine how much they are valued:

"My husband and I are embarrassed by some of our earlier writings when we called them **the retarded** *or even worse —* **retardates.** *(pause) We wish we could forget such things."*

"We are getting messages from across my country from people who live with a handicap that they do not want to be called **retarded.** *And I don't think we can keep ourselves from addressing this issue because if we, on one hand, say we must listen to our friends who have a handicap and, on the other hand, call them a very distasteful label they do not want to be called . . . then we're not listening."*

"I speak as a politician. And I must tell you that — especially with developing countries — it is better and takes less energy to get such concepts right in the beginning. And since we as an international body speak to officials, politicians and those who control the lives of these children and adults . . . we must be careful to talk about them as **citizens,** *as* **people,** *as* **persons** *and as* **human beings** *and never as an entity which is only a disability."*

"I know this can lead to an editorial nightmare. But as a writer, I'm willing to carry the nightmare on my back if it will finally get a worse night mare off the backs of persons with handicaps."

This document utilizes the recommended formula. With the exception of quotations, the **person** is written first and the person's **condition** is second.

Developing nations beware of building residential institutions. It was agreed such places do not help children to develop into the best adults they could be. Representatives from nations having these large, expensive, segregated facilities advised emerging nations to keep from getting caught in the same trap:

"We have learned that these people can become better adults when they live in their own community, and good services and support are provided for them there. Once we build large institutions, they become terribly expensive to maintain, and those who live in them have a terribly hard time getting out. So we don't feel that institutions are the best alternative at all. A recent manifesto titled **The Community Imperative**[3] *has thoroughly and carefully shown in detail why this is so."*

"I belong to an organization made up of people from Mexico, Canada and the United States, called The Association for the Severely Handicapped (TASH— formerly The American Association for the Education of the Severely/Profoundly Handicapped, AAESPH), and in our recent meeting we passed a series of resolutions. The first was to work for the rapid termination of institutions as they exist; and secondly, to work for a rapid closing of segregated schools. Then, in turn, we voted to work for a variety of domestic living, vocational, recreational, leisure and educational services that are community-based and heterogeneous."

"Where individuals with mental retardation have an opportunity to live like the rest of us in the community, they have been met with acceptance, even in places where initially there was resistance to their moving into the neighborhood. Once people actually encounter such persons, they are frequently not just tolerant but sympathetic and supportive, as has been documented so well by a participant in this symposium."[4]

"I remember a statement in an earlier symposium (Airlie, Virginia, USA 1976) when the representative from Jordan, Lena Saleh, said, 'We, in one sense, are fortunate that we have been a deprived country. In the past, we have

[3] **The Community Imperative: A Refutation of All Arguments in Support of Institutionalizing Anybody Because of Mental Retardation.** *The Center on Human Policy, Syracuse University, Syracuse, New York 13210, USA. 1979.*

[4] *Perske, Robert.* **New Life in the Neighborhood (How persons with retardation and other disabilities can help make a good community better).** *Abingdon Press, Nashville, TN 37202, USA. 1980.*

not had the resources to build institutions and therefore we don't have to deinstitutionalize. Now, we can do the right thing for our children from the beginning.' "

Self-advocacy: the most exciting breakthrough of all.[5] The Airlie Symposium of 1976 paid little attention to the idea that persons with handicaps could represent their own interests. Not so in 1979. Within the past three years, self-advocacy became one of the brightest efforts in the field. Throughout the world, persons with handicaps are developing bold new efforts:

- Small group mutual support meetings (helping one another to solve problems each group member is facing in everyday life)
- Self-assertiveness classes (helping one another to speak for themselves and to speak at public meetings and hearings, as well)
- Testimony before lawmakers (speaking about their own human situation and rights)
- Advocacy strategy meetings (speaking on behalf of another member who has been devalued or denied a basic right)
- Annual conventions (organizing and carrying out the programs and paying the bills themselves)

The presenter recently attended such a convention in Massachusetts:

"I was amazed to see how these people participated. Their theme — which they chose themselves — was 'Yes we CAN.' The C.A.N. stood for **change attitudes now**. *They reported on all the things they did this past year. It was an amazing number of things. One of them had to do with getting antidiscrimination legislation passed so they would not be turned away from restaurants, from banks and other facilities in the community. They did it in one year. The governor signed this law a few weeks ago . . . . Isn't that great? . . . Yes we CAN."* (The presenter passed out convention badges with this theme imprinted on them — a gift to every representative from the participants of this self-advocacy convention.)

The group predicted that a future symposium will focus entirely on self-advocacy.

ILSMH: a base for a "school without a campus." Many of the representatives lamented that outdated literature keeps many countries — especially developing ones — in the dark about the latest innovations in the field. In one case, a recent prestigious textbook in psychiatry so devalued persons with retardation that it provoked a massive protest by advocates and consumers. Feeling the pressure, the author and publisher corrected and updated the material. This situation and others like it raised a crucial issue described here by one representative:

"It is difficult in any country to get the latest information in the field. This is especially true in developing nations. We need some sort of course which the League might offer . . . some sort of ILSMH school . . . a school without a campus. It would be a program directed toward planners, parents and governments of all kinds of countries. It would help people to keep up on the most current thinking in the field . . . . Here we have the opportunity to build on the assets of the League. After all, the League doesn't have much money or power. The big asset of ILSMH is people (parents, friends and professionals) who have worked in the field of mental retardation for many years. And those of us who are current in our thinking need to be organized in order to pass on what we know to all the nations."

The discussion of this situation led to a formal recommendation to the ILSMH General Assembly.

(See recommendation on following page.)

[5] *In this report,* **advocacy** *is a non-legal term. An* **advocate** *is a citizen who represents the interests of another. A* **self-advocate** *is one who speaks out on behalf of himself or herself.*

THE FORMAL RECOMMENDATION FOR AN ILSMH TRAINING INSTITUTE

It is recommended that the International League of Societies for the Mentally Handicapped examine the feasibility of setting up an ongoing training institute that should mainly serve the needs of planners (professionals, parents and government officials) and assist them in assessing the most recent and valid trends in services for persons with a mental handicap.

It should be the objective of such a service to enable parents, associations, professionals and governments of emerging as well as more developed countries to give new impetus and new directions to the policy-making process in the field of mental retardation in their countries. This aim could be achieved by:

- reviewing basic philosophies
- assessing new trends and ongoing changes
- acquiring additional knowledge in particular areas
- discussing with experts possible strategies for concepts and implementation

To that end, training programs should be put together that draw on the experience and knowledge of those men and women who have for many years been fighting for full participation of persons with handicaps (through a range of community-based services) on a national and international level.

THE FAMILY — GROWING TOGETHER[1]

"The family as a social system is an organization of individuals who stand in a dynamic interchange with the environment. The interdependence of the family members is such that anything that affects one member has either a direct or indirect effect on the other members. Thus, the attitude of the parent has a direct effect on moulding the personality of the child.

"If this is true of normal children, it is especially true where the child with mental retardation is concerned.

"It has often been said that the home is the nest from which the birds must learn to fly. It is, therefore, the utmost responsibility of the parents to prepare the children by giving them the necessary education for the day when they will leave the home. If the child is mentally retarded, he or she must be given the same opportunities as the brothers and sisters — to be educated, to reach maximum potential and to prepare for the day when he or she will learn to fly and leave the nest, too.

"Never should we put a limit on our expectations, for by so doing, we limit a child's possibilities, too."

The presenter, a parent of a child with mental retardation, began with these unequivocating words.

She, like others at the symposium, experienced such frustrations, adjustments and victories within her family. And she knew her family — and others like hers — must ultimately grow toward unconditonal acceptance of the child with a handicap if they would truly grow together. If it didn't happen, the other outcomes were grim opposites: non-acceptance of the child with the handicap, the disintegration of some family relationships, and the possible institutionalization of the child.

In response to the presenter's remarks, the representatives created a list of key elements families need.

ELEMENTS IN INTERVENTION SERVICES

Ideally, services to families having children with mental retardation would:

- begin at birth
- provide at least one contact person who is on call to the family
- acquire and disseminate the most current information on mental retardation
- provide an array of specific, basic services to the family and the child as needed
- facilitate financial assistance
- make sure all services are part of a continuum so that one can lead into another
- facilitate legal advice
- provide education for siblings and other close relatives
- schedule regular conferences to assess and update an individual's program plan
- ensure the rights of the person with mental retardation to become an adult and maintain a healthy relationship with the family
- encourage voluntary associations to train and assign another parent of a child having handicaps for parent-to-parent contacts
- work for the training and assignment of special advocates to the family and/or the child as specific needs arise
- be flexible in order to meet specific needs of the child and the family

The group predicted some positive outcomes when these elements are applied:

[1] *Based on a working paper by Montserrat Trueta de Trias (Spain).*

- Medical teams will have the information and the skill to refer parents to these special family services as soon as it is learned that a child is retarded.
- Hospitals and mid-wives will take responsibility for putting parents into contact with the special family services.
- Parents will receive immediate support and training services.
- Siblings will be helped to have an active, give-and-take relationship with the brother or sister having retardation.
- The home environment will be strengthened so that the child can remain at home during childhood and adolescence.
- The problems of working mothers will be considered and alternatives will be provided for the in-home care of the child.
- Services already available for all children will expand to take care of children with mental retardation.
- The education of the parent will go hand-in-hand with the education of the child.
- Parents and professionals will think of themselves as partners.
- Advocate roles will be clearly defined and incorporated into the service efforts.
- Advocates will be properly trained.
- Voluntary efforts will be attractive and dignified, making it easier to motivate and retain the best volunteer workers.
- The rights of the parents to assume responsibility for their child will be ensured.
- Parents will be helped to make appropriate decisions about their child.
- All available services will have easy accessibility.
- The rights of the child to become an adult will be ensured. BECOMING A FULL-FLEDGED ADULT WILL BE THE MOST IMPORTANT LONG-RANGE GOAL.

The points of this report are not academic speculations. These are the outcomes of sharing times when each representative told of personal experiences from his or her own country.

On the innate wisdom of some siblings:

"In one family when the boy with Down's syndrome was born, there were three other children: a boy of 13, a girl of 11 and a girl of 3. When the parents were at a point of total rejection, trying to find a home in which to place the child, it was the 11-year-old sister who spoke the following words and opened the door which led to total acceptance of the infant: 'But he is our **brother**!' *And the parents had to admit that she had taught them a lesson, for indeed he was her brother and as such he was, above all, their* **son**.

"As my other children grew they let us know about the mistakes we as parents made with the son who was retarded. Even though they are now grown up, they remind me that I and my husband did not demand as much from the son with the handicap. Sometimes, they were much brighter than we were about how children should be prepared to face life."

Giving within a family becomes a two-way proposition:

"I think we have emphasized how brothers and sisters always should be giving to the sibling with the handicap. And we have understressed the fact that this particular child needs to give, too. After all, there is a strong connection between giving and growing."

Support the family first:

"In my country the people who have been in the position of helping families have not done it in the home . . . they have spent hundreds and hundreds of dollars per month to support the child outside of the home . . . while not one cent is offered to support the child within the family."

Families need reliable contacts:

"We need a fixed point of contact and a single person who is on call at all times. For too many years, we have been told by one agency to go to another . . . . They just kept passing us on and we never did get the help we needed."

"In Sweden, every family has a special telephone number, and there is someone on the other end of the phone all of the time."

"In England, the Warnock Report calls for a named person for every family, someone who is

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always responsible. And, of course, as the child gets older and moves into other services, that named person changes."

Experiences with medical personnel in one country:

"Some hospitals do not want it known that a child with retardation was born there, and they do everything they can to get rid of the parents and the child as quickly as possible. The diagnosis is given with a sense of shame as though what had occurred was the parent's fault and as though the physicians were afraid they might be blamed for the child's mental retardation. No help or information is offered; the parents are treated as though theirs was the first and only child born with a handicap."

Medical attitudes in another country:

"The physicians are often misinformed. For instance, some parents are told their child will outgrow the difficulty, while others are told of the hopelessness of their child's condition. Mental deficiency is considered an incurable disease by the medical profession, and hence as hopeless. What is more, the total non-existence of the study of mental deficiency in most medical schools deprives the students from learning about how to help parents of children with retardation."

On parents' rights versus the child's rights:

"Although parents often make decisions that are in the best interests of their child, this is not always true. A few feel that their child can only go so far, then he or she must be given 'crutches' and be heavily protected. I'm aware of what the law says at this point because I am studying family law just now. And there is a great battle going on. The issue: Where do the rights of the parents stop and the rights of the children come forward? Some time ago, I was in the court, fighting parents who had decided that they did not want to die thinking their offspring was going to be out in the community. They felt this way even though the staff at the institution said, 'The person should leave the institution. He is ready. He can handle it and live alone.' And yet, the parents said, 'No.' They said, 'He must stay in the institution. We cannot die happily unless we know that he is protected.' These parents were defeated in the court case . . . and rightly so."

Voluntary associations can develop parent-to-parent involvements as no one else can:

"One of the unique contributions voluntary associations can make is in organizing parent-to-parent relationships and parent advocacy efforts. We have learned that the training and assigning of skillful parents to other parents will never be done by anybody else as well as these associations can do it. After all, such organizations have parents with on-the-line experience, and they only need to be channeled into relationships with other parents by responsible coordinators. I think this is the number one contribution these associations can make."

Before the parent movement started, such statements were unthinkable. Then, parents received more incentives for sending their children away to institutions than for keeping them at home. The members of this symposium called for a halt to such family separations. They called for incentives which would enable parents to keep the child at home, to help parents grow close to their children and to help them become respected citizens in the community. This would amount to a turnaround in society's thinking.

EDUCATION FOR LIVING[1]

The presenter, in his working paper, began by comparing the development of two 25-year-old women with Down's syndrome. During childhood, both sets of parents chose to keep them in the home. However, they lived in different communities, and they experienced different attitudes and expectations in their educational programs. Consequently, there was a difference in the way they functioned by the time they had reached young adulthood:

"Soon after Sue Smith was diagnosed as having Down's syndrome, her parents contact local school district officials for advice. They were told over the phone that Sue was not eligible for public school services until she was five, but at that age she would be eligible for a program for Down's syndrome students in a special education school. Since she lived a sixty-minute bus ride away from the school, she spent two hours every day riding a bus with other severely handicapped students. When Sue reached the age of eighteen, she was transferred from her segregated school program to a sheltered workshop located across the parking lot from the school. Sue is now 25 and lives with her mother and father. Each workday, she is picked up by a bus upon which the phrase 'Independent Living' is painted, and she is delivered an hour later to the sheltered workshop where she 'earns' approximately three dollars per week."

"Soon after Beth Jones was diagnosed as having Down's syndrome, her pediatrician immediately contacted local school district officials. School personnel then made plans with Beth's family for immediate home and school-based education and its related developmental services. During the first five years of her life, Beth attended a public school program close to her home that contained other handicapped as well as non-handicapped students. At age five, Beth was placed in a kindergarten program that was taught jointly by a regular kindergarten teacher and an early childhood special education teacher. At age six, Beth was placed in a class of severely handicapped students in a different regular elementary school. At age 12, Beth was placed in a class for severely handicapped students in her local junior high school, and between ages 15 and 21, she functioned in a similar class at her local high school. Throughout her school experience, a variety of strategies were implemented to ensure that she interacted with non-handicapped peers of the same age and other persons in a variety of school and community environments. Consequently, at age 21, Beth was able to function quite well in a group home which contained both retarded and non-retarded persons in the same age range as hers, and she was supervised by non-handicapped adults only slightly older than she. Also, at age 21, she obtained a job as a part-time dishwasher at a local cafeteria and she used public transportation to go to and from work. Her job paid the minimum wage and she was eligible for many employee benefits. Beth has now been working at her job and living in a group home for four years."

Beth Jones was educated in the public school system of Madison, Wisconsin, USA. Seven key characteristics govern this educational program:

Zero rejection. No child with a handicap is rejected (by a public school) because he or she cannot fit into existing programs. Instead, the system builds the individualized educational program any child needs — even if he or she has severely or profoundly handicapping conditions.

From birth to 21. If a child is born with a handicap in this city, he or she is enrolled in

[1] *Based on a working paper by Dr. Lou Brown (United States).*

public school and begins receiving in-home or in-school education immediately. The educational curriculum is arranged so that children with handicaps are mixed with those who are non-handicapped. The school system views such peer-group interaction as a powerful educational tool for both those with handicaps and those without.

Chronological age schools. All children go to regular schools appropriate for their age. There are no segregated schools for those with handicaps. Also, the children go to a school as close to their own home as possible.

Current and future environments. Curricula help students to function as well as possible in real community environments, and to prepare them for life in environments in which they will someday live. In order to make this preparation as complete as possible, the **least restrictive, most nurturing environment** is identified for each child. Then, the person is helped to live as well as he or she can in that setting. ("Just because some may never learn to read or write does not mean they must be treated like babies all their lives. Instead, we expect them to someday function as real adults as much as they possibly can.")

A normal ratio. The ratio between those with handicaps and those without is kept as low as possible. If five or six children living in the same school attendance area have the same handicap, it is better to have their classes in the local school instead of busing them across town where a larger concentration of such children exists:

> *"Whenever you pile kids with handicaps up, they lose. It enables the rest of us to see them as 'they,' 'them,' 'the retarded' . . . as groups of people who show up at the state fairs as large globs of persons with retardation . . . and to transport them on buses with strange names painted on them. This is what keeps us from seeing them as 'John,' 'Sue,' or 'Sally' — as real individual human beings we can get to know and love in spite of their handicaps."*

Natural environments. Curricula are designed to take a person to a natural environment and to teach him or her to function well there. For example, one learns how to cross a street best by crossing a **real** street. Consequently, much of the educational curriculum takes place at various locations in the community and not merely in the classroom. Of course, much of this community-referenced education happens in teacher-to-student ratios ranging from one-to-one to one-to-five, never in large groups of 15 to 20 students. ("We teachers used to assume that we were responsible for getting students to do things in the classroom during the school hours only. After that, how they functioned in the home or on the street was assumed not to be our problem. We don't assume such things anymore!")

Zero inference. Once upon a time, teachers inferred that whatever a child was taught in a classroom automatically transferred into better functioning at home and in the community. Now, they infer no such thing. The teacher cannot feel he or she has successfully taught a skill to a child until that boy or girl can perform it well in a variety of settings outside the classroom.

* * * * *

As the representatives discussed the seven characteristics in detail, many interesting rationales supporting the concepts emerged:

Interactions between those with handicaps and those without. It became clear that when children with handicaps go to school in the same building as non-handicapped ones, **both** receive a better preparation for living in the real world. This even applied to students with the most severe handicaps:

> *"Children with severe and profound handicaps need to be in regular schools, too. The interaction between these handicapped students and other students is utterly remarkable. The future parents of such handicapped children are in the schools, today. And what kind of attitudes, values and expectations will such parents need? Also, future doctors, teachers, lawyers, policemen and ministers are in the schools, too. They need to grow up with such children so they will understand them and not reject them. Therefore, we are making conscious and systematic attempts to make sure that every student has some kind of interaction with handicapped people . We train regular students to handle seizures in school . . . to work with handicapped students at recess, in the gym and the swimming pool . . . to hire out as baby sitters for handicapped children . . . to help with transportation problems . . . to wheel handicapped students in wheelchairs to and from school. In many cases, regular students receive class credit for their involvement with handicapped persons."*

Teachers without classrooms. Some teachers work fulltime taking students out of class for training in the regular city buses, restaurants, shopping centers, post offices, and to every facility they can think of that ordinary citizens use in their everyday living. They teach people to live in the community by actually **being in it.** First, teachers go side-by-side with the students, carrying out every step in sequence. Then, as individual students get to the point where they can accomplish specific tasks without help, the teachers slowly withdraw.

The principle of partial participation. If teachers recognize that students with handicaps cannot do all steps in certain task sequences that so-called normal boys and girls can do, it does not mean they should be kept from doing the steps they can. Some examples:

"If a student needs assistance carrying his tray, he may be able to use the school cafeteria successfully. In our view, providing a student with the personal assistance necessary to go through the cafeteria line with non-handicapped peers is preferable to having a student eat lunch in his classroom with only other severely handicapped students."

"Assume that a severely handicapped student cannot perform all the skills required in a particular group home necessary to make toast. However, if the household supervisor arranges the essential materials, the student can put the bread in the toaster, depress the lever, remove the toast, and place it on a plate . . . In our view it is worthwhile to arrange materials so that severely handicapped students can participate in such activities."

"Assume that a student is handicapped in such a way that she cannot toilet herself. Unfortunately, what usually happens is that the adolescent or young adult is laid on a mat on a classroom floor and diapered. Often it is judged that the student will never acquire the skills necessary to toilet herself and that because she cannot perform **all** *the skills in the sequence, she should be almost totally dependent on others for her toileting needs. The position offered here is that we should constantly explore ways that will allow such students to 'participate in the process.' For example, we might try to teach her to raise her bottom off the seat of her wheelchair, using her elbows and shoulders so that her diaper can be changed without her having to leave the wheelchair."*

Early intervention programs using teachers. More and more teachers work side-by-side with medical personnel, eliciting and reinforcing healthy development with newborn children having handicaps. The presenter gave an interesting rationale for such innovative teamwork:

"When you get a kid at birth, there are important advantages. Chests tend not to collapse because of poor positioning; self-stimulation and self-mutilation tend not to develop; the range of motions that you really want later on tends to develop . . . all those things happen early. There is a tremendous difference in the development of these children and those who are discovered after five years of staying at home with no assistance."

A thoughtful woman from one of the struggling, less fortunate countries said she felt depressed after comparing such rich educational efforts with those taking place in her own country. Then, after a moment of silence, she said, **"Every child in the whole world should have a public school education like that!"**

OUT OF SCHOOL — THEN WHAT?[1]

The presenter predicted that numerous programs — especially industrial ones — would spring up throughout the world within the next few years. Some participants felt so strongly about this they called for a future symposium dealing wholly with adults having handicaps.

International documents lend support. The presenter described five key international documents that supported an emphasis on the adult with mental retardation.

"The United Nations Universal Declaration of Human Rights (1946), which in Articles 22 and 23 assures everyone both the right to social security and the right to work.

"The United Nations Declaration on the Rights of Mentally Retarded Persons, 1971, which states the right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his or her capabilities.

"Recommendation 99 Concerning Vocational Rehabilitation of the Disabled of the International Labor Organization (ILO) 1955, (this may be called the 'Magna Carta' of vocational rehabilitation of the disabled; it covers physical and mental impairments).

"Resolution Concerning Vocational Rehabilitation and Social Reintegration of Disabled or Handicapped Persons, ILO, 1975.

"The United Nations Declaration on the Rights of Disabled Persons (1975), which requests governments to endeavor to assure for all categories of disabled persons — physical, sensory and mental — care, education, training, vocational guidance and suitable work as well as social security benefits."

Optimism in spite of labor problems. The presenter's paper contained a long list of barriers to productive employment that adults with mental retardation experienced in the past. Nevertheless, the presenter's attitude was far from pessimistic:

"I would like to suggest quite a bit of optimism in our approach. There is no reason to be discouraged by the long list of barriers . . . . We are far too often overwhelmed by what we consider the complexity of the problem. We should take them step-by-step . . . and each barrier we overcome will provide added energy and courage to tackle others. So let's not try to solve the total problem at once, but let us try to find pilot examples and concepts that will keep us in a constant process of solving the larger one."

The representatives did exactly that. So many ideas were volunteered that the discussion session was extended for an extra hour. Some interesting ideas were discussed:

Disenchantment with sheltered workshops. Many saw sheltered workshops as closed settings. Alternatives in the real world of work were sought:

"Sheltered workshops are more often than not artificial alternatives, and when you look at them closely they are not really even training environments. Instead, they are **holding** *environments. Why? Because a person gets put in one . . . . The staff say they are training the person, but one can come back ten years later to find the person doing the same tasks. Quite often, the 'trainee' is worse off because during the past ten years he has been learning bad behaviors from the other so-called trainees . . . and he or she is less ready to go out into community jobs than prior to admission to the workshop. When that happens, all you have is another bad detour a person must take before moving into real adulthood."*

[1] *Based on a working paper by Dr. Walter Eigner (Austria).*

The redirection of funds. Many participants felt that a high percentage of industrial training funds are locked into outmoded programs:

"In our country we are struggling to redirect massive amounts of money invested in sheltered workshops in order to supply real employers with incentives and supports for training and employing persons with handicaps. It is our belief that this transfer must sooner or later take place because we feel such businessmen will do a better job — and they will do it with less money."

No-nonsense placement is crucial. A key weakness in past industrial placement programs has been the persons doing the placing. Placement personnel trained only in the social services usually do not understand business management. Consequently, they emphasize the "charity" of hiring persons with handicaps and play on employers' guilts and sympathies. The representatives felt that such charitable approaches are wrong. "Employers do not even have to like employees with handicaps," said one representative. "Managers don't always like their non-handicapped employees — they need to know only that their employees are doing their work well."

In a government report passed out to the representatives[2], a new breed of placement worker was described:

"When a placement worker from this small, hustling, avant-garde vocational training unit approaches an employer to discuss the hiring of a TALL (the agency acronym for Training Alternatives for Living and Learning) client for a specific job opening, there's no defensiveness in his approach. There's no gingerly holding of hat in hand, nor saintly expression, nor enticing the employer to feel sorry for the client. Instead, a hard-nosed business deal is offered.

"The placement worker goes over the employer's detailed list of skill requirements and may even add a few more . . . . Then, component by component, the TALL representative goes over the handicapped person's profile with the employer, showing that this worker can meet every . . . requirement.

"When such discussions have concluded, the employer is often amazed because the placement worker — who was expected to be a 'social service type' — turned out to be a no-nonsense businessman who talked the employer's industrial language. And, by skillfully matching the employer's data with the client's profile, the placement worker is frequently able to convince the employer that what his company stands to gain is a good, productive worker."

Innovative employee-to-employee support arrangements. The representatives were favorably impressed with the "Pathway Scheme" as highlighted in the opening session. They liked the idea that a regular employee would receive a small sum of money for helping to facilitate the adjustment of a new employee with a handicap. They predicted the development of more planned peer-group arrangements throughout the world within the next few years.

Formal approaches to labor unions. It was agreed that well-planned, formal meetings with these powerful organizations needed to be set up now. One representative suggested having special meetings with union members who are parents of persons with handicaps.

Special incentives for employers. The Association for Retarded Citizens (USA) national On-the-Job Training Project received recognition as an innovative model worth replicating elsewhere. Since 1966 the Association, with government support, has placed persons in competitive work settings where they receive special training on the job. A financial supplement is provided for the employer during the initial employment period in order to offset the cost of training. During the first 14 years of the project, more than 25,000 persons with retardation have been placed.

In the real market place. The group lamented that many industrial training programs take place in simulated work settings located apart from the real world of work. Such arrangements have at least one serious drawback: the step from artificial training program to real industry becomes so great that even so-called normal persons would have a hard time making it. Therefore, the group recommended that industrial trainers bring vocational training programs as close as possible to the practices and locations of regular industry.

The Donut Shop, in downtown La Mesa, California[3], was discussed as one model. This small bakery employs three bakers, five salespersons, an administrator and a vocational teacher. An average of 12 vocational trainees (persons with

[2] **Mental Retardation: The Leading Edge — Service Programs That Work.** *The President's Committee on Mental Retardation. Washington, D.C. 20201, USA. 1979. (Single copies are free.)*

[3] *ibid.*

retardation) work side by side with the regular employees in this unique learning-by-doing enterprise.

Team arrangements for those who can't compete as individuals. Of course, competitive employment remains as a major goal for preparing persons with retardation for adulthood. But what about those who simply can't compete? The representatives talked about team operations which are known as "work enclaves" in some countries and "work stations in industry" in others. Many take place in regular factories, like Volvo automobile plants in Sweden; in agricultural settings and orchards, like those in Israel; and in Community Redevelopment Teams in Los Angeles, California[4]. Most of these teams use the "peer-group principle" developed by Emanuel Chigier of Israel. One leader explained the principle as he saw it:

> *"None of these projects could ever be completed by any of the workers alone, but together they became a remarkably powerful construction force. That is why we emphasize that they belong to a very good group."*

Hopeful views in developing countries. The representative from Kenya helped the symposium participants to learn that those from less industrialized nations have many interesting things to contribute to the working world of persons with handicaps:

> *"In Kenya, 90 percent of the citizens with retardation still live in the countryside. And they often do whatever the others are doing: they take care of the cattle, and they are just another member of an extended family enterprise. Therefore, we are taking great care not to copy everything the industrialized nations are doing....We know we must train each person to work with his own hands and to use his own sweat in a task as well as to work as one member of a larger family."*

Consequently, citizens with handicaps learn to operate small hand looms for making rugs and doing other kinds of one-person tasks. Such operations take place everywhere in Kenya. A member of the group spoke of one young man with retardation who takes pictures of people for money:

> *"When he saw me, he walked up and asked to take my picture. Since I knew him earlier, he said, 'You see, I'm all right now. I'm wearing a suit and I'm earning my money. I'm not begging in the street anymore.' Here was a good example of a man who was trained to do his own work and to remain as a part of an extended family."*

Teaching functional skills in schools. Many of the representatives felt that the school curricula should be functional; they should develop self-reliance and contain elements "hardening" one for productive work:

> *"We have a principle that states, 'Never teach a child something the teacher does not have to do.' Here's how it works: Does a teacher have to prepare and pass out juice? Then, teach it to the child. Does the teacher have to put a coat on a child if he or she can't? Then teach it. Actually, there are so many functional things children with handicaps must learn in order to be an adult."*

The greatest goal: pride in one's work. A representative from Martinique introduced the idea that no matter what a person's vocation, he or she should be doing something that gives a satisfying sense of accomplishment. "The pride that comes from doing something well," he said, "is what makes people really feel like accomplished adults." Another representative added, "In most getting-acquainted conversations, the 'second question' is 'What do you do?' and if the conversation is to continue with mutual respect, each must speak with pride about what he or she does for a living." Artificial tasks in many outmoded industrial training settings keep some persons with handicaps from speaking with pride about what they do. Consequently, the group affirmed that "service delivery agencies should help their trainees with handicaps develop such meaningful vocations that they will be able to answer that second question with pride."

[4] *ibid.*

THE WORLD AROUND[1]

A remarkable number of interdependent relationships take place between ordinary persons and the world around them. They happen with such regularity one pays little attention to how many there are.

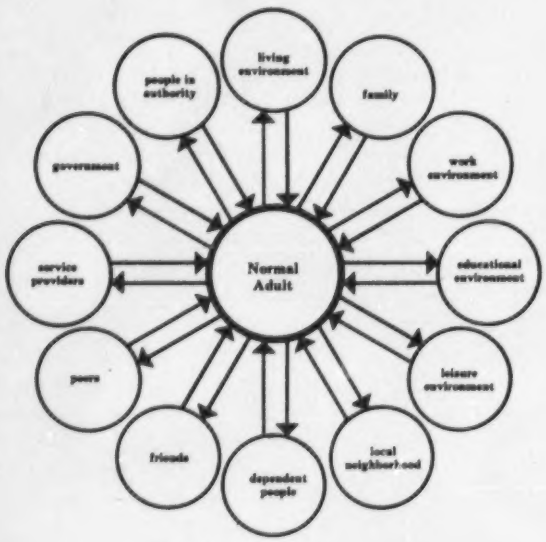

Figure 1 The Environment of the Normal Adult

Figure 1 shows that for normal people, solid give-and-take interactions (signified by the arrows) take place between them and a wide variety of entities in their environment.

Figure 2 The Environment of the Adult With Retardation

In Figure 2, depicting how the world around impinges on persons with retardation, it can be seen that many linkages are tenuous (broken lines) or nonexistent (absence of lines):

- Many have little choice concerning the nature of their **living environment** and they often have few opportunities to change it.
- Sometimes the family is the only contact they have.
- For many in the presenter's country, linkages with the world of **work** are only theoretical.

[1] *Based on a working paper by Dr. Barbara Speake (England).*

- **Leisure and friendship** opportunities remain less than they should be.
- The diagram shows that most persons with retardation have absolutely no one **dependent** upon them for anything. And in a world where one's self-esteem is influenced by being worth something to others — to really be needed — this may be the most tragic aspect of all.
- Linkages with **government, people in authority and service providers** only have a one-way influence.

The diagram gave representatives a clear view of the true human situation of persons with retardation. It helped them find out exactly where they were in their efforts to help such people.

Instead of discussing all twelve linkages, the group focused on only one: work environments, making use of foundations built in the previous sessions. The group emphasized 16 directions:

- Have an individualized vocational plan for each person. ("We want to emphasize **individualized** because when we don't, that's when we get into trouble. That's when we build workshops for **them** and not **him** or **her**.")
- Start vocational training early and continue throughout life. ("Some call it career education. It impresses upon educators that their students are going to grow up and get old like other people.")
- Make training as natural as possible. ("Too many programs are artificial, unnatural, nonfunctional and meaningless.")
- Develop a wide variety of individualized work models. ("One model simply won't fit all towns and countries. Therefore, find as many models as possible and share information on them.")
- Make specific work skills a part of the tools. ("The training must be more than teaching work skills. Attitudes, appearance, proper social behavior and pride in one's work must be taught as well.")
- Placement is not enough. ("Too many are placed and forgotten and they have no help when it is really needed.")
- Have a variety of funding patterns. ("Too often a single funding pattern usually earmarked for workshops determines the development of all people with retardation. The funds should be flexible and applicable to many alternative programs.")
- Have a healthy transition between school, later vocational training and jobs. ("Too often, there is a bad gap — an abruptness — between one program and the next. There needs to be a natural, logical transition.")
- Delineate a wide range of support services, ("Our people can learn to do the job all right. But they need supports for proper behavior during breaks, social relationships in the evening, recreational opportunities and anything else that will help them to live well in the community.")
- Compile a listing of good vocational preparation services from all over the world and design strategies that can be used to localize the best of such services. ("We feel this could be one of the tasks of the Training Institute recommended in the first session. Also, give the advantages and disadvantages of each service and show which ones are appropriate for certain types of communities and countries.")[2]
- Compile listings of all good laws, policies and administrative codes relating to vocational opportunities for persons with retardation. ("The recommended Training Institute could take this on as another project.")
- Share demonstrations of success in order to change attitudes. ("One of the best things about this symposium has been the chance to share the good breakthroughs. Everybody needs an opportunity like this.")
- Organize international technical assistance teams. ("You can only do so much with the printed word. Therefore, there is a need for teams of people to interact with one another. Such arrangements could be sponsored by the Training Institute as well.")
- Explore the use of quota vs. employer incentive systems and good handicapped-to-nonhandicapped ratios. ("We need to find as

[2] *Note: It has been learned that the International Labor Office will carry out such a project in 1981, the International Year of Disabled Persons.*

many ways as possible for integrating a healthy number of people with handicaps in industries and the community at large.")

- Have pride in the products. ("Persons need to feel a satisfaction in their finished work. They must see meaning in what they are doing.")
- Honor the rights of the employees. ("We should make sincere, conscientious efforts to secure the preferences and values of the person who is handicapped when we are making vocational decisions.")

THE WORLD WITHIN[1]

This session took an interesting turn. In the previous periods, participants said what they felt needed to be done to and for persons with mental retardation. Now, the participants faced a different challenge. It became clear that all the bold new technologies and attitudes they had been talking about could not be carried out as effectively as possible without all participants being well-skilled in one more task: They needed to learn how to **listen** to persons with handicaps, too.

The presenter's paper contained excerpted quotations and conclusions taken from tape-recorded conversations of 30 persons with handicaps who participated in a series of low-key discussion groups and individual interviews. Some spoke candidly for themselves, while others, having speech impediments — or no speech at all — had to be watched patiently and listened to by "helpers"[2] until they were understood.

"Perhaps the only thing they had in common was the label **mental retardation**," the presenter said. "In this sense, much of what they said had to do with **labelers** as well as with themselves, the labeled."

The following conclusions became apparent:

Parental and professional fears. Those with handicaps told how parents and professionals were fearful for their safety and security. They saw this fear as one of the major hindrances to their development. A 25-year-old man described the effect of such wavering confidences:

"My parents and the staff of the residence I lived in did not feel that I was competent to live on my own. But in my heart I knew I was ready to move on and also believed that I had to move on in order to feel like an adult. I discussed it with the staff and they were very uneasy about it. They told me I wasn't ready. They convinced me to stay for another 6-8 months in the residence. I admit I was getting restless and my confidence wavered somewhat. Finally when they said it was probably O.K. for me to move out into an apartment, I got cold feet."

Finally, the young man did go out on his own. Although he experienced some painful crises, he became successful at living alone and ultimately leaving a sheltered workshop for competitive employment. His later reflections were revealing:

"It seems to me that we just have to go out and do some of those things. Most often because no one will believe we can do them and they tend to overprotect us, even ruining our own confidence with their fears about our failing. Sometimes we have to fall and hurt ourselves."

Painful segregation. The presenter described the apartness people with handicaps are often forced to experience.

"The problem of separation from 'normal' people is seen as a major factor in delaying the development of the person who is mentally handicapped. This delay is manifested in a number of ways. First, it does not allow non-handicapped people the opportunity to meet with their peers who happen to live with a handicap. Second, it does not provide any role modeling and other learning opportunities for the person with a handicap. Third, the separation of 'normal' people from others has an indisputable negative effect on the self-concept of persons who are handicapped. Institutions, they say, are the epitomy of this."

A 22-year-old man recalled such separations in his childhood: "People seemed to close the door on me as a person. They separated me." According to him, people never seem to take time to look past the handicap to really know him. Said he, "Because of my slurred speech and difficulty in walking, I think a lot of people decided I was drunk or on a trip."

[1] *Based on statements by members of North Shore People First, a self-advocacy organization in Vancouver, British Columbia, Canada. Their thoughts were written down by Jo Dickey, David McCoy and other members of the Community Living Society. Jo Dickey served as presenter.*

[2] *In many self-advocacy organizations, members with handicaps have chosen to designate as* **helpers** *all non-handicapped persons — professional and volunteer — who are invited to work with them.*

Powerlessness. Some of the most touching communications dealt with how people having handicaps had been rendered powerless by others. Sometimes it happened brutally. For example, one young woman described how she had been demoralized by a professional who was testing her — he pointed out all the tasks he thought she could never do. Looking back on the experience, she realized that she proved many of his predictions inaccurate. Nevertheless, she — like others who received such flattening experiences — harbored bitterness and resentment because it happened, and she only recently dared to speak about it to anyone. Now, she felt she could defend herself.

Low self-concepts as adults. Some admitted that they had a hard time coming of age. They blamed this delayed development on the low expectations others held for them.

One young woman of 25 explained how she felt:

"I still can't think of myself as an adult, even though I am. I feel like I haven't grown up. It seems that I am going through my teens now, you know; I just started dating a few years ago. In some of the jobs I've had in a sheltered workshop, they called me a kid. Sometimes people still call me a little girl and tell me to do things. I bet no one would say that to you.

"People never really started talking to me about being an adult until I was 21. I don't know why they didn't start when I was 13 or 14. All of a sudden, when I turned 21, people started telling me I had to be an adult. The day before, though, they treated me like a child and still do sometimes."

One of the most poignant self-concepts came from a man of 22:

"When I think of myself as a child, I see an object that stands there and waves goodbye. That's right, just stands and waves and waves goodbye. Have you ever seen the institutional kids waving?"

These statements came only after helpers thoroughly prepared themselves to really hear what the members of this self-advocacy organization had been trying to say for years. The experience reminded the presenter of a statement by Andre Gide:

"Everything that needs to be said, has already been said. But since no one was listening, everything must be said again."

• • • • •

Toward becoming a skillful listener. One does not become a helpful listener overnight after many years of **ignoring** persons with handicaps. Nevertheless, representatives shared what they knew about developing sensitivity and receptivity.

- The presenter, the parent of a son with a handicap, confessed she learned how to skillfully listen to such people only three years ago.

  "It has been one of the richest experiences I've had . . . learning how to be a listening helper to such people. It took a tremendous amount of finesse and receptivity, and I had to look within myself and change some of my own attitudes toward people with handicaps, too . . . .

  "I learned that messages are not just given verbally. Sometimes they are given by motion — motion of the head, the eyes, even the whole body . . . . Sometimes when a person can't stand something anymore, he wets his pants or does some other aggressive action in order to say, 'Hey! You've put me in a position that is intolerable and I can't deal with it anymore.' I learned that it is possible to interpret such actions and get a clear message."

- Another participant described how any minority being liberated from the oppression of a majority will speak out in a very unsophisticated manner at first. Such was the case of black communities in the United States in the 1950s. But the more they did speak out through the years, the more detailed, the more sophisticated they became in communicating their human rights and values to others. The People First organizations across North America are following the same course, and their increasing sophistication is more apparent each year.
- A participant who attended the 1978 National meeting of the Canadian Association for the Mentally Retarded described an interesting turn of events. Many members of People First organizations attended that national meeting, too. And in the plenary sessions, they interrupted the speakers from

time to time, asking questions or making statements. These communications were respectfully received and what they said was valued. Not so very long ago, persons with handicaps would have been quieted when they spoke out like that.

- The presenter described her confidence in people with handicaps who are honestly listened to.

"At first, don't be surprised if they talk bitterly about the frustration of being misunderstood, ridiculed, over-protected, ignored and separated. I have traveled across my country listening to people tell of the tremendous outrage they feel.

"But later, as you help them build confidence, as they talk about themselves, it's almost as if you can hear them saying, 'How am I doing? . . . Am I sounding OK?' And when you honestly tell them when they are doing well, they cherish your responses.

"Still later, they become more calm and purposeful about what they are saying and doing."

STRONG OUTCOMES

Representatives shared with one another examples of what can happen when people begin to listen skillfully to persons with handicaps:

Self-advocacy. Slowly but surely many persons with retardation are speaking out on their own behalf as they have never done before. Also, they are speaking out on behalf of one another. Organized self-advocacy groups based their power on these two actions.

According to the presenter, "Helpers should only help a few persons with handicaps to develop their strengths and then let them develop the organization. There is always a danger," she said, "that people having handicaps can be manipulated into being orators for us . . . people who will only front for our ideas. This is destructive, and it is not the type of self-advocacy they need."

At a government hearing in Washington, D.C., a representative was so moved by the success of these self-advocacy organizations, he said, "The time has come when many persons with handicaps will save themselves."

One participant possessing better than 40 years of service to persons with retardation, said, "I have seen many exciting things happen down through the years, but none excites me as much as self-advocacy organizations do."

Philanthropy. One man bought a home with the help of a self-advocacy organization. He wrote a will bequeathing the home to the local voluntary association. In the will he provided that the association should rent the home only to other persons with handicaps. If they failed to do so, the will provided for the home to be sold with the proceeds going to the self-advocacy organization he belonged to.

Board members. Numerous voluntary associations and community-based agencies reported that persons with retardation serve as members of the organizations' official policy-making boards. To make sure that they were not "token" members, one organization assigned "helpers" to sit with those officials having handicaps. Then, when necessary, the helpers carefully explained each issue **sotto voce**, enabling persons with handicaps to see issues clearly and to vote according to their own consciences.

Heroism. In one country, six men were drowned in a river while trying to save each other. One was a professional counselor and the other five were persons with retardation. Afterward, many organizations only recognized the counselor as a hero. Later reflections helped one participant to see how "in the past, civilization — because of its own sense of uncertainty, weakness and distorted needs — was often unable to recognize handicapped people as heroes." He elaborated:

"After all, if I'm acting as if I'm strong and heroic, when internally, I don't feel like I'm very much, something within me can forbid that I recognize one of **them** *as a hero. Nevertheless, the more I feel OK with myself, the less I need to waste time on bluffs like that.*

"Today, I have a fresh opportunity to search among the cowards of the world for heroes. (After all, heroes are really cowards who 'hung in there' longer than the rest of us.) And this time, with our new views, some heroes with handicaps will be right up there on the list with non-handicapped ones. Now, my list contains... a man with Down's syndrome who died trying to pull his brother out of a burning house . . . a woman with cerebral palsy who pulled an angry, biting dog off a seven-year-old child . . . a woman with Down's syndrome who stayed all night at the bedside of a seriously ill, elderly neighbor."

Giving. In one country, older persons with handicaps serve as tutors for younger ones — helping them to "make it" in the community. They go to restaurants, cinemas and sporting events and the older persons with handicaps help the younger ones learn how to conduct themselves. In the same country, people with retardation have discovered that elderly persons in nursing homes are lonely and in need of their friendship, too. Consequently, **giving** relationships are developed with elderly persons. One representative described the importance of such an attitude:

"They must be allowed to give to other people. And if they are not allowed to be givers in the world, too, they will suffer the worst anguish that a human being can ever experience."

LOVE, TENDERNESS AND MARRIAGE

The last reporting session approached the time when symposium participants usually feel they have shared enough. Not so at this symposium. The representatives decided to tackle one more issue: sexuality.

One mother spoke of her early astonishment when a counselor stated that her son "was capable of a continuing relationship with a person of the opposite sex." Said the mother:

"At first, I was puzzled by what the counselor said. Then I felt pretty good about it. After all, I know many 'normals' who aren't capable of long-term relationships with the opposite sex.

"I was aware that my son had a strong attachment for a young woman he had befriended at a camp they both attended for many years. So I wrote the woman's parents, asking if they would be interested in helping my son and their daughter to develop a respectful marriage. They said no.

"Well, that was that . . . But I continue to think that my son's life would be richer if he had someone to come home to . . . a warm, loving other person to turn to.

"Now that he's 30, I continue to worry about his needs. And I'm not just talking about sexual activity because I consider that as only a part of a much larger act of caring and loving. And I know he'll never be capable of supporting himself totally . . . . I know he will need support persons — and some parts of our country have such people. I feel he needs some truly caring person — a partner — to turn to."

In the United States, in the spring of 1979, two national television broadcasting companies presented two-hour, prime-time television dramas dealing with love and marriage between persons with retardation. It was reported that the Columbia Broadcasting System produced **No Other Love** and the one aired over the American Broadcasting Company, **Like Normal People**, was based on a book with the same name, written by newspaperman Robert Meyers.[2] Both of these television specials received national honors and high audience ratings. Meyers' book received national honors as well.

Until a few years ago, men and women with handicaps had been forced to exist apart from each other. Most institutions of the past were laid out so that dormitories for males and females were situated on opposite sides of large grassy expanses of land. Men and women were together in places like dining halls; but even then, they did not sit together, and they were never beyond the watchful eyes of their caretakers. All longings for close friendships with the opposite sex were blocked.

Of course, other parent representatives shared how their sons and daughters were simply not interested in the opposite sex, or they still functioned in stages where their strongest love was for a professional working with them, or interactions with the other gender were childish. "Fine. If that is where they are, recognize it and don't make a big deal out of it," said one of the participants. It was added, however, that "We will never really know where they are in their relationships with the opposite sex until we seriously listen to them and help them feel some responsibility for such choices."

The session went overtime. This session simply could not close until the difficult subject of sexuality was faced. It logically followed that if the time has come to listen in depth to what persons with handicaps want to say to us . . . and if they will be allowed to speak for themselves . . . and if we are truly inclined toward cheering them on to a full-fledged adulthood — then **our** views of **their** sexuality must change, too. And evidently they are. For example, one representative reminded us of a time, some 20 years ago, when the standard acceptable rule was "No alcohol or sex if you are retarded."

[2] *Meyers, Robert.* **Like Normal People.** *New York: McGraw-Hill, 1978. (Published in London by Souvenir Press, 1979.)*

CLOSING MOMENTS

Usually symposium participants use the last moments to summarize all that has already been said — to organize all the key items as if to place them neatly in a box and close the lid. Not this group. They went to work, checking their emphases one more time and searching for any crucial new directions which they perchance had missed. So when participants at such meetings are usually closing down, these folks were opening up.

The group utilized an intriguing system for making sure of the major emphases and for gathering additional information:

- Each person received five cards.
- A how-best-to-do-it question was posed for accomplishing the major goal expressed in each of the five major sessions.
- Then, the representatives — using a single sentence — wrote on each card what they felt was the most important action needed in accomplishing each goal.
- Each group member read aloud what they wrote on their five cards.
- The actions were written on a blackboard and tallied for emphasis.
- Those actions receiving the major emphases were discussed one more time.

The five questions and the responses they evoked:

How to help prepare persons with retardation for life in a workaday world. The answer: **Begin right from the start.** Better than half felt this was the strongest point. The time for preparing persons for the workaday world must literally begin at birth.

How to help persons with retardation speak for themselves. The answer receiving the most emphasis was clear and sharp: **Listen to them.** Of course, the listening will not be easy after many years of ignoring and believing that these persons don't really have anything to say to the rest of society.

How to broaden education to develop skills to deal with the real world. Three answers were emphasized: (1) **Teach in an age-appropriate environment.** In other words, everything in the educational environment should reflect the true age. No longer should adults or adolescents be taught as if they were babies or small children. (2) **Teach a realistic curriculum.** What will a person have to know in order to "make it" in the real world? When these things are known . . . teach them. (3) **Teach in a natural setting.** The representatives, by this time, believed that such education must not take place in artificial settings. This means the regular school buildings are the best settings for educating persons with handicaps — the same buildings attended by non-handicapped persons. And only those with severe medical problems might, because of their fragile constitutions, have to be educated in a setting other than regular ones.

Expanded discussions on these actions uncovered additional thoughts:

- **Ordinary teacher and student awareness.** "Everyone in regular school systems must become aware that persons with handicaps belong in their schools and they will be with them from now on."
- **Added burdens on regular schools.** "We recognize how regular education will be challenged to go beyond what they ordinarily do to educate people. This will be an added burden. But this shift must be seen as corrective. After all, persons with handicaps are human beings, too. And they are worth every bit as much as so-called normals."

- **The dignity of risk.** "Such risk-taking is very much a thread that runs throughout education. You and I learned some things only after we fell time and time again. Then, we picked ourselves up and made it. Although I'm talking about **prudent** risk, my non-handicapped son explains it better than I can when he tells me his brother with retardation has 'the same right as anyone else to be hit by a car!' "

How to expand the connections with the world around. Again, better than half of the participants emphasized a single action: **Integrate persons having handicaps with non-handicapped people.** Once the myths and fears about persons with handicaps are diminished, both those with handicaps and those without will be better people because of the interpersonal skills that can be developed from such relationships. During the discussion, one more valuable direction was discovered:

- **Cosmetic intervention.** "Those with handicaps have the right to be as attractive as possible. If a young woman has excessive hair on her face, she has the right to have it removed . . . If her teeth are rotten, she has just as much right to make those teeth attractive — or receive good looking false teeth . . . The same can be said for changing unsightly glasses . . . even hair styles."

Said another, "They have the right to have cosmetic surgery as well."

Another mentioned that in his country, some plastic surgeons are performing surgery on persons with Down's syndrome — removing tissue from the epicanthic folds around the eyes, correcting the nose structure and reshaping chins as well.

How to help the family grow together. The unanimous emphasis: **Provide a comprehensive program of early intervention services.** These services should be delivered to the child with a handicap as soon as he or she is born (or identified as a person with a handicap). At the same time, other services should be provided for the parents and the siblings. Early interactions between the family and its helpers (both professional and volunteer) can help the family to grow together as no other actions can. During the discussion, it became clear "the family is by far the most important social unit and there is no other grouping on the face of the earth that can take its place." Then came a touching but provocative new direction:

- **The right to a family.** Said one representative, "If the family of a child with a handicap cannot fulfill this right, **that child has the right to another family.**"

* * * * *

Then came the time to say goodbye to one another. The participants — in spite of cultural and geographic differences — had indeed been close.

As they returned to various parts of the world, one issue remained vivid in everyone's mind: For years societies unwittingly allowed persons with retardation to be "frozen into a continuous state of becoming prepared to enter adult life, yet not enabled to reach it." The light that was cast on this single demeaning human situation in the first session drew the participants together in a remarkable way. And they departed with a determination to do everything they could possibly do to help the child with retardation today to break through into a fullfledged adulthood tomorrow.

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Declaration of general and special rights of the mentally retarded

Whereas the universal declaration of human rights, adopted by the United Nations, proclaims that all of the human familly, without distinction of any kind, have equal and inalienable rights of human dignity and freedom;

Whereas the declaration of the rights of the child, adopted by the United Nations, proclaims the rights of the physically, mentally or socially handicapped child to special treatment, education and care required by his particular condition.

Now Therefore

The International League of Societies for the Mentally Handicapped expresses the general and special rights of the mentally retarded as follows :

ARTICLE I

The mentally retarded person has the same basic rights as other citizens of the same country and same age.

ARTICLE II

The mentally retarded person has a right to proper medical care and physical restoration and to such education, training, habilitation and guidance as will enable him to develop his ability and potential to the fullest possible extent, no matter how severe his degree of disability. No mentally handicapped person should be deprived of such services by reason of the costs involved.

ARTICLE III

The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to productive work or to other meaningful occupation.

ARTICLE IV

The mentally retarded person has a right to live with his own family or with fosterparents; to participate in all aspects of community life, and to be provided with appropriate leisure time activities. If care in an institution becomes necessary it should be in surroundings and under circumstances as close to normal living as possible.

ARTICLE V

The mentally retarded person has a right to a qualified guardian when this is required to protect his personal wellbeing and interest. No person rendering direct services to the mentally retarded should also serve as his guardian.

ARTICLE VI

The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If accused, he has a right to a fair trial with full recognition being given to his degree of responsibility.

ARTICLE VII

Some mentally retarded persons may be unable, due to the severity of their handicap, to exercice for themselves all of their rights in a meaningful way. For others, modification of some or all of these rights is appropriate. The procedure used for modification or denial of rights must contain proper legal safeguards against every form of abuse, must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic reviews and to the right of appeal to higher authorities.

ABOVE ALL
THE MENTALLY RETARDED PERSON
HAS THE RIGHT TO RESPECT

The International League of Societies for the Mentally Handicapped

USA 15c
International Year of the Child